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## Chapter

# Spirituality and Hansen's Disease: Spirituality's Conceptual Structure and Hansen's Disease History - Part One

*Makiko Kondo, Mikako Yamaberi, Hitomi Yamao, Masato Muguruma, Kayoko Furochi, Shiho Oka and Aiko Matsushita*

## Abstract

There have been suicides at the Hansen's disease sanatoria in the past. What is the level of suffering that makes a person think of suicide? This study is divided into two reports. In the first report, we demonstrate the conceptual structure of spirituality and the relationship between quality of life (QOL) and spirituality, and the history of Hansen's disease. In the second report, based on the first report, we will show spiritual pain and spiritual well-being experienced by Hansen's disease survivors through an analysis of their life reviews. When our daily lives are calm and mundane, we do not notice spirituality. However, when we confront hardships of life, for example, diagnosed with leprosy and isolated in a sanatorium for life-time, we notice spirituality as an existential distress. On the other hand, the development of individuality and imperturbability by overcoming hardship is spiritual well-being. Spirituality serves as the existential foundation for human existence and is important for the relationship with "something greater than self." Spiritual well-being is one of multiple dimensions of QOL.

**Keywords:** Hansen's disease, spirituality, spiritual pain, suicide, spiritual well-being, gerotranscendence, life review, Leprosy Prevention Law

## 1. Introduction

Hansen's disease has been stigmatized from ancient times. Patients were forced to live in sanatoriums for their entire life, and this forced some of them to commit suicide. Although a sanatorium was a medical institution, it had a crematorium, an ossuary, and religious facilities (see **Figures 1–4**). Religion was used for saving the patient's soul.

What is the level of suffering or "spiritual pain" that makes a person consider suicide? What causes spiritual pain in those suffering with Hansen's disease? The experiences of Hansen's disease survivors are important to order identify the essence of spiritual pain, which remarkably decreases their QOL. On the other hand, Hansen's disease survivors who had suffered spiritual pain were eventually freed of their



**Figure 1.**

*First Ossuary. The 674 people who passed away between 1901 and 1936 are buried here. The oldest remains are dated June 12, 1901 (Oshima Sanatorium opened on April 1, 1901).*



**Figure 2.**

*Ossuary. A majority of the residents lived here for the rest of their life and were cremated here. Those whose remains were not returned to their hometowns are kept in this ossuary on the island.*

sufferings and went on to become latter-stage elderly living vividly with purpose of life, even though it was minor. Is it possible to develop an individuality wherein one can experience spiritual well-being despite having experienced spiritual pain? This is an important theme, as spiritual well-being constitutes a part of QOL.



**Figure 3.**  
*The 88-stature circuit within Oshima Seisho-en property. A total of 88 stone images are enshrined on the property to permit the 88-temple Shikoku pilgrimage to be carried out on-site.*



**Figure 4.**  
*Dance of the Wind. The title, “Dance of the Wind,” is based on the following wish: “at least let the spirit of my dying words ride the wind away from the island, freely released to return to my native home.” It was built by approximately 1000 volunteers in 1992. The pointed conical monument on the front represents “everything in the heavens and space above,” while the conical platform in the back represents “everything under the sun on earth.” The round area with flagstones is a stage on which souls are thought to dance with the wind before setting off to their hometowns. The conical monument contains ashes of many individuals that did not entirely fit within their funerary urns.*

This study is divided into two parts. In the first report, we describe the conceptual structure of “spirituality” and the relationship between spirituality and QOL. In the second report, we show the spiritual pain and spiritual well-being of Hansen’s disease survivors through a review analysis and discuss spirituality and QOL. A table content of the first and second report is presented in **Table 1** as an overview of the entire study.

## 2. Quality of life and spirituality

### 2.1 What is quality of life (QOL)?

Characteristics of QOL include considering the health and happiness from the perspective of the subject. It emphasizes subjective over objective evaluation,

Part one	Part two
<p>Spirituality's conceptual structure and Hansen's disease history</p> <p><b>1. Introduction</b></p> <p><b>2. Quality of life and spirituality</b></p> <p>2-1. What is quality of life (QOL)?</p> <p>2-2. What is spirituality?</p> <p>2-3. Development of spiritual pain into cancer terminal care</p> <p>2-4. Spiritual pain and total pain</p> <p>2-5. What is spiritual well-being?</p> <p>2-6. Quality of life and total pain</p> <p><b>3. Overview of history of Hansen's disease in Japan</b></p> <p>3-1. From the ancient times to the end of the feudal era ( -1867)</p> <p>3-2. From establishing a modern nation (the Meiji government) to the end of World War II (1868-1945)</p> <p>3-3. From developing the magic bullet 'Promin' to abolishing the Leprosy Prevention Law (Act No. 214 of 1953 らい予防法) (1943-1996)</p> <p>3-4. After abolishing the Leprosy Prevention Law (1996-)</p> <p><b>4. Life review of Hansen's disease survivors</b></p> <p>4-1. Introduction to the National Sanatorium Oshima Seisho-en, where the survivors who have shared their life review live</p> <p>4-2. The life review book of Hansen's disease survivors</p> <p><b>5. Conclusion</b></p>	<p>Accounts of spiritual pain and spiritual well-being by Hansen's disease survivors</p> <p><b>1. Introduction</b></p> <p><b>2. Spiritual pain experienced by a Hansen's disease survivor</b></p> <p>2-1. The life review of Hansen's disease survivors</p> <p>2-2. Overview of Mr.Takahisa Yamamoto's life review</p> <p>2-3. Analysis method for construction</p> <p>2-4. Construction of Mr. Takahisa Yamamoto's spiritual pain</p> <p><b>3. The process of recovering from spiritual pain for a Hansen's disease survivor</b></p> <p>3-1. What sustained Mr.Takahisa Yamamoto through the suffering?</p> <p>3-2. Relieving sufferings; preparing to accept turning points</p> <p>3-3. Turning point 1: Changing the flow of life</p> <p>3-4. Turning point 2: Meeting a friend for life (Ceramics)</p> <p>3-5. After the turning point</p> <p><b>4. Spiritual well-being of aging Hansen's disease survivors</b></p> <p>4-1. How do individuals live energetically despite having experienced extreme situations?</p> <p>4-2. Construction of spiritual well-being; Introduction of the study</p> <p><b>5. Conclusion</b></p> <p><b>Appendix</b></p> <p>Mr. Takahisa Yamamoto's life review (An excerpt only from the section that discusses spiritual pain)</p>

**Table 1.**  
*Table contents about the first report and the second report about 'Spirituality and Hansen's disease'.*

and the evaluation of multiple dimensions rather than a single dimension. The primary goal of nursing is enhancing the QOL of a subject and the results of nursing intervention can be evaluated by the QOL.

By Haas' QOL model [1], if the four dimensions that are physical, psychological, social, and spiritual, indicate well-being, the QOL is high.

## 2.2 What is spirituality?

The Old testament, states: "God made person from mud and breath in its nose, and then the mud figure become living human." Therefore, we believe that the source of life is from the breath given by God. Spirit comes from the Latin word "Spiritus," and the elements that make the human are body, mind, and spirit.

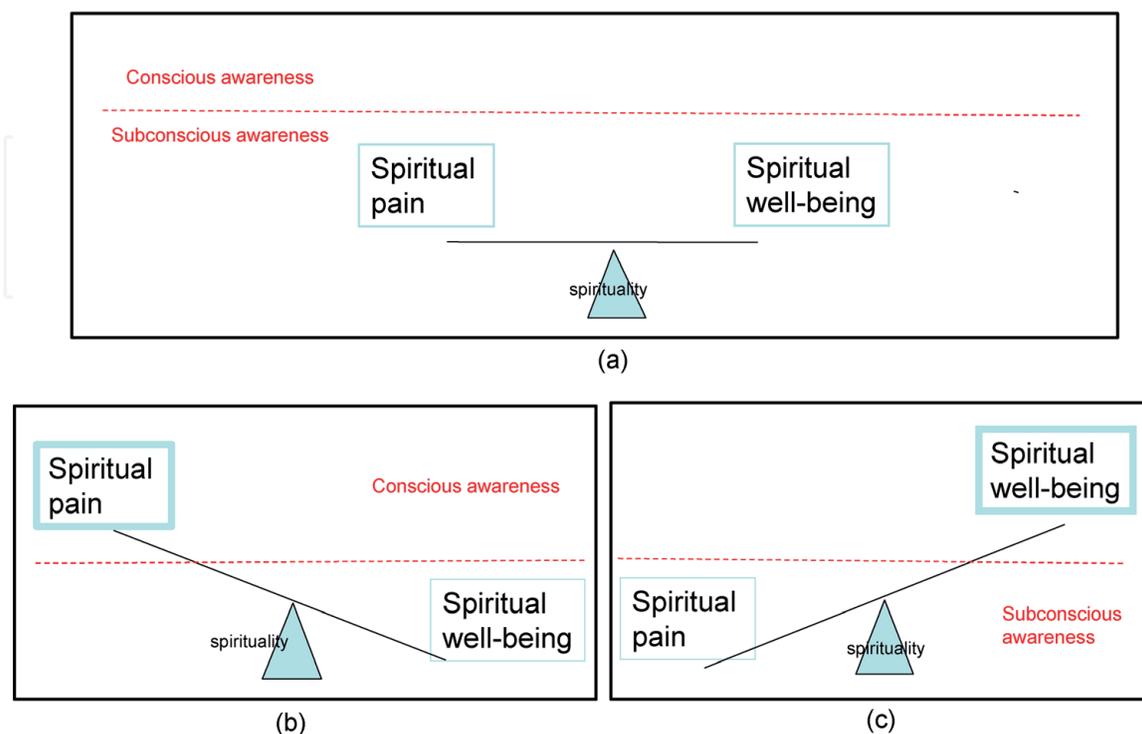
When we encounter a crisis in life and lose our identity or the existing framework for living like other human beings and leading life in our own way, we seek the framework of transcendent power that exists outside us or the ultimate core within us. This function is known as spirituality [2].

**Figure 5** shows the relationship between spirituality, spiritual pain, and spiritual well-being. At the time when we have control over our life and can live in our own way and like other human beings, we tend not to notice spirituality, as we are not philosophers who think about life and death everyday see (**Figure 5(a)**). Although when faced with a crisis, for example the news that we have cancer or Hansen's disease, or see our own people dying, lose family members in an earthquake, or face other sufferings that make us think of committing suicide, we feel spiritual pain and notice spirituality see (**Figure 5(b)**). On the other hand, spiritual well-being became apparent in some people, for example, those who have a peaceful death or are deeply religious see (**Figure 5(c)**).

### 2.3 Development of spiritual pain into cancer terminal care

Spiritual pain has been important in terminal care for cancer patients. The reasons for this are mentioned below. The first, cancer has the stigma of death attached. After being diagnosed with cancer, patients have to reconsider their life plan and think about where they want to live, who do they want to live with, and how do they want live the rest of their life. The second, dying patients can see the signs of their end coming closer as their physical condition and activities of daily living (ADL) decline gradually. Facing one's death leads to despair and spiritual pain. The third, the understanding that their family will lose a loved one. Death of a loved one means losing the future of living with the loved one, therefore to deal with this grief a lot of psychological energy is needed.

## What is spirituality?



**Figure 5.** (a) Not actualized spiritual pain and spiritual well-being (life as usual); (b) actualized spiritual pain; and (c) actualized spiritual well-being.

## **2.4 Spiritual pain and total pain**

The experience that terminal cancer patients undergo is called “Total Pain.” Total pain encompasses physical, psychological, social, and spiritual pain [3]. Physical pain includes various factors like body aches, difficulty in breathing, fatigue, and also difficulties in ADL like eating, sleeping, and moving. Psychological pain includes feelings of anxiety, loneliness, anger, irritation, etc. Social pain is related to work problems, financial issues, problems in the family, inheritance issues, etc. Spiritual pain implies questioning the meaning of life, pursuing God, changes in the value system, a search for the meaning of suffering, fear of death, feeling of guilt, etc.

It is difficult to distinguish between psychological and spiritual pain. Psychological pain implies that the mind is functioning against the body, on the other hand, spiritual pain means questioning the relationship with something greater than self or something that is transcendent [4]. Therefore, spiritual pain exists when we question the meaning of life and existence. For example, when we cannot meet a loved one or a partner and feel lonely because of the physical distance, it is psychological pain, but when we lose a loved spouse and suffer and contemplate suicide and blame God for the loss, it is spiritual pain.

Spiritual pain is expressed as: (1) unfairness: why did I get this disease?; (2) unworthiness: I do not want to become a burden on my family; (3) hopelessness: there is no meaning in doing that; (4) guilt: it is my fault; (5) isolation: no one understands me; (6) vulnerability: I do not have the ability; (7) abandonment: God is not helping me either; (8) punishment: I am being punished and that is why I have cancer; (9) confusion: why must I suffer even if there is God; (10) meaninglessness: my life is meaningless [5].

## **2.5 What is spiritual well-being?**

There are very few patients who have a sense of gratitude and peace as they face death as compared to the number of patients who have total pain. There are some who try to find the meaning of suffering when they are afflicted with hardships of life like, a massive earthquake, loss of a loved one, loss of work, divorce, etc. Spiritual well-being implies being in harmony with self, others, nature, and something greater than self, and the process of finding the best meaning [2]. People who have faith in God in daily life can find the meaning of suffering and are peaceful while facing death and hardships as compared to people who do not have faith. Therefore, it can be said that religion leads to spiritual well-being. At the same time, religion is not the same as spirituality. All persons with or without faith have spirituality. Therefore, all humans have the potential to develop at the level of the soul even in extreme situations until the moment of death.

## **2.6 Quality of life and total pain**

By Haas’ QOL model [1], if the four dimensions that are physical, psychological, social, and spiritual, indicate well-being, the QOL is high. QOL and total pain are the two sides of the same coin, which implies that if the four dimensions are painful, then the patient has total pain, and if the dimensions indicate well-being, the patients level of QOL is high. Ensuring a patient’s well-being in all four dimensions is the aim of the practice of nursing.

## **3. Overview of history of Hansen’s disease in Japan**

It would be help to divide this into four periods to facilitate better understanding: (1) From the ancient times to the end of the feudal era (the Edo period); (2) From

establishing a modern nation (the Meiji government) to the end of World War II; (3) From developing the magic bullet “Promin” to abolishing the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法); (4) After abolishing the Leprosy Prevention Law.

### **3.1 From the ancient times to the end of the feudal era (~1867)**

Leprosy existed in Japan from the ancient times and statements about the disease were mentioned in *Nihon Shoki* (AC.720), which is one of the two oldest written documents in Japan. According to the concept of defilement, Hansen's disease patients were considered to be defiled beings because of their change in appearance. In Buddhism, leprosy is considered as a punishment from heaven and a disease caused because of karmic retribution. Patients stayed at home so that they do not stand out, or lived in areas that were designated for the feudal outcast group and thus coexisted in society. Patients who could no longer live in their hometowns would beg at the gates of temples and shrines, or depart on wandering journeys and were called “wandering lepers.”

### **3.2 From establishing a modern nation (the Meiji government) to the end of World War II (1868–1945)**

During the Edo shogunate (1603–1868) the society was peaceful and there was no war for 250 years, but this was broken by a bloodless revolution, the Meiji Restoration and the Meiji government was established. The new government made an effort to create a modern nation, make the country economically sound, encourage new industries, and to strengthen the army, in order to prepare for the threats from the Western powers. Unfortunately, the government was a part of the World War II and lost the battle in 1945.

After the Meiji government was established, Hansen's disease was considered as a “national disgrace disease,” in addition to a “heavenly punishment disease” and “defilement disease.” The Government believed that the sight of patients begging at shrines was symbol of a country that was not civilized. This was considered a national disgrace as the government aimed to make the country a civilized country. According to the concept of national purification and the idea of supremacy, patients with Hansen's disease as well as weak and disabled people were excluded. In line with militarism, Hansen's disease patients were treated coldly during the war because they did not contribute to military strength and the disease was mostly seen in young men.

In addition, bacteriology and the study of public health were introduced, leading to the use of isolation to prevent infection. By similarly to the acute infectiousness of cholera according to theory of social protection, general people misunderstood as terrifying infectious disease.

Based on the above background, the government forced lifelong isolation and internment in order to eradicate Hansen's disease, and established sanatoria and legislations to legalize forced isolation. In 1907, the Leprosy Prevention Law (Act No. 11 of 1907; 癩予防二関スル件) was enacted in order to force patients who did not have relatives and were known as “wandering lepers,” to intern at sanatoria. Five sanatoria were established across the nation. In 1931, the Leprosy Prevention Law (Act No. 58 of 1931; 癩予防法) was enacted to isolate patients living at home and did not force internment by police authority. In 1929, the Leprosy-Free Prefecture Movement started spreading. This movement was aimed at tracking all patients, reporting them, and interning them at the sanatoria so that there would be no patients living in the prefecture. As a result of this movement, the feeling that Hansen's is a horrible infectious disease took root among the populace.

The treatment offered to the patients at the sanatoria during that period had serious issues from humanitarian and ethical perspectives. For example, the patients were forced to undergo sterilization surgery in order to prevent them from having children, they were forced to enter the punishment room, officers had disciplinary arrest rights which was the right of the sanatorium director to punish or confine patients who disobeyed the rules at his own discretion, sanatorium scrip which was an attempt to prevent runaways by converting money to a currency that could only be used in the sanatorium, changing names to an internal alias, forced labor, establishment of diseased/non-diseased boundary, autopsy, and so on. One of the biggest issues was that the Hansen's Disease Prevention Law did not have any stipulations about being discharged. Therefore, once a person entered a sanatorium, there was no possibility for them to get discharged.

### **3.3 From developing the magic bullet “Promin” to abolishing the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法) (1943–1996)**

Japan lost the Second World War in 1945 and a new constitution which respected basic human rights and advocated democracy was established in 1946. In addition, the magic bullet “Promin” was developed in USA in 1943, and after the success to synthesize the chemical in Japan in 1946, treatment using the same was started in 1947. The conventional law, the Leprosy Prevention Law (Act No. 58 of 1931 ; 癩予防法) was amended and the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法), which emulated the conventional law and continued to grant disciplinary arrest rights and forced internment, was established. This was going backwards and was against the intent to promote respect for basic human rights and democracy after the war, and was adopted even though the disease could be cured with Promin. In addition, in spite of furious opposition, through hunger strikes and abandonment of sanatorium work, by the National Hansen's Disease Sanatorium Residents' Council, the opinion of authority in the Leprosy academic meeting at that time were adopted.

The National Hansen's Disease Sanatorium Residents' Council negotiated with the government persistently, which led to the buffering on the regulation on going out, but this came to a standstill in operational mitigation because of the abolition of the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法) in 1996.

### **3.4 After abolishing the Leprosy Prevention Law (1996~)**

After the abolition of the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法) in 1996, during the National Redress Suit in 2001, the government was convicted to have committed a mistake by promoting the policy of isolation. The government, including the Prime Minister; the House of Representatives and the House of Councilors; and the Minister of Health, Labor, and welfare, apologized to the Hansen's disease survivors. Only a few Hansen's disease survivors could return to social existence as the average age of these people was over 60 years. The Law on Promoting a Resolution for the Hansen's Disease problem was established in 2009. This law directs that these patients are guaranteed that they would be able to lead a normal life, get treatment, return to the society and will be offered aid for social life, also that assistance would be provided to redeem their reputation, protection would be provided for family members, and the dead would be memorialized.

The average age of Hansen's disease survivors currently is 86, and the total number of people with the disease has decreased to 1175 as of 2019. There will be no cases of Hansen's disease in Japan soon. Now, high quality nursing is provided in the sanatoria. With this we hope that the aging Hansen's disease survivors, who have previously experienced suffering and hardship, can have a peaceful life and

live with purpose. We are hopeful that the survivors, who do not have children and grandchildren because of the sterilization surgery, are well cared for by the nursing staff and can have a peaceful death.

## **4. Life review of Hansen's disease survivors**

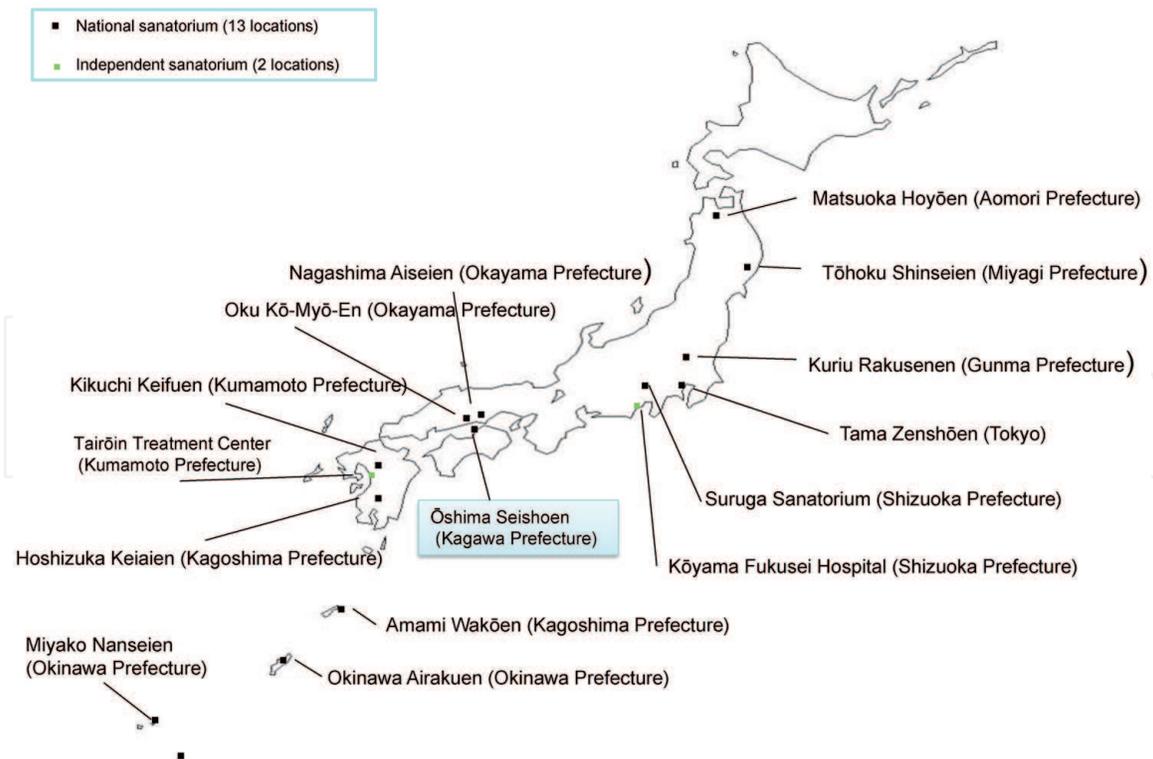
### **4.1 Introduction to the National Sanatorium Oshima Seisho-en, where the survivors who have shared their life review live**

A national sanatorium, Oshima Seisho-en was established under the Leprosy Prevention Law (Act No. 11 of 1907; 癩予防二関スル件) and it has 110 years of history. Oshima island is in Seto inland sea, and one can get there on a ship. The distance from the nearest harbor in the mainland is 8 km. Oshima is a small scenic island with a total area of seven kilometers, and has a mild climate. The island is seven kilometers. The number of residents recorded during the war was about 740. As of August 2019, the number of residents is 52, the average age is 84.3, and the length of stay of these residents is 57.6 years. After the abolition of the Leprosy Prevention Law, many people have visited the sanatorium to learn about human rights, and some foreigners visit the island during the Setouchi Triennale. See **Figures 6** and **7(a)** and **(b)**.

### **4.2 The life review book of Hansen's disease survivors**

We published a life review book about 19 Hansen's disease survivors living at Oshima Seisho-en [6]. From chapter 2 to 20, each chapter describes the experiences of one person. Each survivor talks about their childhood before having Hansen's disease, the shock and suffering that followed the diagnosis, till the time that they entered the sanatorium, discrimination and exclusion in their hometown, the parents affection and worry to protect them, inconvenience faced by their brothers and sisters, various symptoms and cures, the bad experiences in the sanatorium, romantic alliances, support from friends at the sanatorium, fighting against the government, current feelings and thoughts in their old age. The subject of the book is summarized as "Deeply Deeply Closing Our Eyes in Order to See What We Truly Should See," which is the subtitle of the book and has been penned by poet Ms. Yoshiko Takagi.

The significance of the book is discussed in the following eight points. (1) Negative history about medical care and administration at the sanatoria has been mentioned from the perspective of the survivors as a subjective experience, therefore, their narration is important as a primary resource to share the history of the disease with later generations. (2) When the principles of medical ethics including, respect for autonomy, beneficence, non-maleficence, justice and/or equality, were violated, what happened? The reality is shared. (3) Discrimination and exclusion against diseases with stigma is not just limited to Hansen's disease. If there is an outbreak of an unknown or lethal infectious disease (ex. Ebola hemorrhagic fever) in future, these experiences will become the lessons to ensure that the mistakes are not repeated again. (4) Their narratives hold value for ethnology, for example, the 88-temple Shikoku pilgrimage accepted wandering lepers and handed them secret medicines from the major Buddhist Kobo Daishi (774–835), and the discrimination and customs of the neighborhood groups in the agricultural society. (5) Their accounts give an insight about the wisdom and strength that made them overcome terrible hardships, and the clear vision that made them accept their life positively. This wisdom and strength has universal value for all human beings and is also



**Figure 6.**  
*Hansen's disease sanatoria nationwide.*



**Figure 7.**  
*(a) View of the entirety of the Ōshima Seishoen (in the background are Yashima and Takamatsu harbor); and (b) view of Ōshima Seishoen.*

useful for people who are currently suffering. (6) The nurses at the sanatorium were the listeners of their life review. This book has also recorded the nursing practices. This interaction also increased the ability of the nurses to listen, empathize, understand, and deepen the relationship between them and the survivors. Through this, the nurses also got the opportunity to care for the survivors who do not have their own children. (7) The book was made by using qualitative and inductive methods in order to arrange the composition and express it in a narrative tone, therefore even elementary students can read it to learn about human rights. (8) New patients of Hansen's disease have been found only in developing countries like India, Brazil, and Indonesia. They account for about 80% of the total patients. The developed countries are not concerned about the disease. We hope that by increasing the awareness in developed countries, through the stories of the survivors, the wisdom and strength for solving problems in future will be shared.

In the second report, we introduce Mr. Takahisa Yamamoto's life review which clearly defines spiritual pain and shows the result of an analysis of questions such as why does a person experience spiritual pain, what is the identified nature of spiritual pain, and how can one recover from spiritual pain.

## **5. Conclusion**

This study comprises the first report and the second report. In the first report, we describe the conceptual structure of spirituality, the relationship of spirituality and QOL, and the history of Hansen's disease. Spirituality was developed as a part of the studies relating to terminal cancer patients who must confront their own death. When our daily lives are calm and mundane, we do not notice spirituality. However, when we confront hardships of life, for example, when we are exposed to the dangers of life, we notice spirituality as an existential distress. On the other hand, the development of individuality and imperturbability by overcoming hardship is spiritual well-being. Spirituality serves as the existential foundation for human existence and is important for the relationship with "something greater than self." In common understanding, QOL is evaluated not objectively but subjectively, and not as a single dimension but as multiple dimensions. Spiritual well-being is one of multiple dimensions of QOL.

In the second report, we will show the spiritual pain and spiritual well-being of Hansen's disease survivors who have lived harsh lives via an analysis of their life review based on the findings of spirituality and QOL from the first report.

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## **Conflict of interest**

We have no financial relationships to disclose.

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